

# Testimony in support of Assembly Bill 659 HIV Testing Modernization Bill

Assembly Committee on Health & Health Care Reform January 27, 2010

Good afternoon Chairman Richards and members of the Assembly Health and Health Care Reform Committee. Thank you for holding a public hearing on this bill.

HIV infection remains a significant public health problem in Wisconsin with approximately 7,000 HIV positive individuals who are reported to be currently living in the state. It is also estimated that there are almost 2,000 residents living in Wisconsin who do not know that they are infected. While efforts to curb this disease have had some significant success over the years, new research and data from around the nation have made it clear that our state laws are outdated and restrictive for both patients and health care providers.

In 2006, the National Center for Disease Control released revised recommendations for HIV testing of adults, children, and pregnant women. These revised recommendations reflect advances in health care services that have been made in the past decade and address many barriers that studies found were preventing individuals from being tested for HIV. While 42 states have laws in place that are in line with the CDC's revised recommendations, Wisconsin is one of the few states that have yet to adopt these new standards.

In the CDC report, many health care providers cited several issues such as Wisconsin's current written informed consent requirements and extensive pre-test counseling as being time-consuming and burdensome. In a survey of health care providers, the CDC found that only 10% of providers encouraged at risk patients to be tested for HIV on-site.

By adopting the CDC recommended "opt-out" consent process, more physicians will be encouraged to routinely incorporate HIV testing and counseling in their care of patients. I strongly believe that this change will not only increase testing rates, but will ensure that patients continue to be well-informed of their health care decisions.

In addition to this change, AB 659 also includes a number of new patient confidentiality and privacy provisions. This bill protects a patient's right to decline HIV testing, clarifies that a health care provider cannot use this decision to deny other services or treatment, and increases penalties for improperly disclosing HIV test results without consent.

In summary, AB 659 will help to adopt the CDC-identified best practices, encourage prevention strategies that maximize voluntary HIV screening rates, and update our state statutes to reflect modern advances in the screening and treatment of HIV infections. This bill will help to bring Wisconsin up to date in our efforts to identify and prevent the spread of HIV and AIDS, and I want to thank you again for this opportunity to testify before you today.

EMAIL REP.SHILLING@LEGIS.WI.GOV



# **AB 659: HIV Testing Modernization Bill**

## Goals of legislation

- Clarify and update testing language
- Increase testing of patients for HIV/AIDS
- Protect patient privacy rights
- Minimize burden on health care providers

## Major Issues Addressed by the Bill

- Informed consent
  - O Currently, patients are required to sign an agreement consenting to be tested for HIV
    - This paperwork is both burdensome for health professionals and also deters some patients from being tested
  - O This bill will eliminate current written informed consent requirements and replace with a model more closely resembling the CDC recommended "Opt-Out" provision
    - Will encourage more individuals to be tested
    - Testing will still be voluntary and a patient's right to decline is clearly stated
    - Will reduce paperwork for doctors and simplify testing requirements
  - The Opt-Out process for obtaining consent is similar to the testing requirements for other STD screening tests

# Disclosure of results and discrimination against people with HIV

- HIV test results should not be disclosed in an inappropriate manner
  - AB 659 provides stronger protections of medical records and increases penalties for discrimination and inappropriate disclosure

# Good Samaritan testing

- o AB 659 would establish a process for testing individuals for HIV who are involved in significant exposure situations under Wisconsin's "Good Samaritan" Law
  - A "Good Samaritan" can request that an accident victim be tested for HIV if there is a significant exposure and potential risk of infection to the "Good Samaritan"
  - If the accident victim objects to testing, the "Good Samaritan" would have to go through the legal process to obtain a court order

## Simplify definition of HIV

- O Statutory language is clarified in the bill
  - Medical advances in the last 20 years have made the old definition obsolete and unclear

# HIV case reporting

O AB 659 allows HIV information and data to be provided to certain public health officials to promote public safety and further HIV prevention efforts



# State of Wisconsin Department of Health Services

Jim Doyle, Governor Karen E. Timberlake, Secretary

> Assembly Public Hearing Committee on Health and Healthcare Reform Wednesday, January 27, 2010

Assembly Bill 659: Related to HIV Consent and Testing Statutes Jim Vergeront, M.D., Director, AIDS/HIV Program, DHS Kathleen Krchnavek, MSW, AIDS/HIV Program, DHS

Chairman Richards and members of the Committee on Health and Healthcare Reform, thank you for the opportunity to speak today on AB 659. We are happy to be here today in support of AB 659. Building upon an Assembly Bill previously introduced by Dr. Sheldon Wasserman, the Department has worked closely with Representative Jennifer Shilling to create legislation that will modernize Wisconsin statutes related to HIV consent and testing. It is our strong belief that enacting this legislation will lead to earlier identification of HIV-infected persons and initiation of appropriate medical that will result in reduced morbidity, mortality and transmission of HIV to other persons.

Wisconsin has a long tradition of establishing HTV-related legislation that is science-based and that fairly balances the public health needs while protecting the rights of an HIV-infected individual. In the early years of the epidemic, significant but appropriate concern regarding HIV-related stigma and discrimination led Wisconsin and many other states to establish informed consent requirements for HIV testing that are much more restrictive than for other diseases.

Wisconsin statutes that have safeguarded the confidentiality of persons infected with HIV and protected them from discrimination in health care, housing, and employment, have been critical to the State's successful response to the HIV epidemic. However, to ensure that we continue to effectively address the HIV epidemic, it is important that we make some changes to our current HIV testing and consent laws. These changes would make Wisconsin law consistent with the HIV opt-out testing that the Centers for Disease Control and Prevention (CDC) recommends. Specifically, to reduce barriers to HIV testing, the CDC recommends that states should not require written informed consent for HIV testing. CDC recommends "opt-out consent" where the provider notifies a patient that an HIV test will be done unless the patient declines.

AB 659 does more than change Wisconsin's HIV consent law. It updates our statutes related to disclosure of test results; HIV reporting; significant exposure provisions; penalties for discrimination and inappropriate disclosure of HIV test results; and it clarifies and simplifies a very complex area of our public health statutes. AB 659 addresses the following areas:

- Written authorization for disclosure would be retained but now would be separated from the process of obtaining consent for HIV testing.
- The local health officer would be added to the list of entities that have legal access to HIV test results for public health purposes.
- "Mode of transmission" would be added to the HIV Case Report, making it consistent with the AIDS Case report, and providing information that is essential for identifying trends in the epidemic.
- Specific conditions related to significant exposure would be revised, including allowing Good Samaritans access to a source patient's test results in specific situations, and enabling HIV test results of an exposed person to be released to the exposed person's health care provider.
- Penalties for discrimination and inappropriate disclosure of HIV test results would be doubled.
- The definition for "HIV test" would be simplified throughout the statutes.

1 West Wilson Street • Post Office Box 7850 • Madison, WI 53707-7850 • Telephone 608-266-9622 • dhs.wisconsin.gov

## HIV infection remains a severe public health problem in the United States and in Wisconsin

- Approximately 1.1 million Americans are living with HIV infection.
- It is estimated that approximately 56,000 individuals in the U.S. are infected annually, and that of this estimate, 21% are infected and do not know it.
- Transmission from persons who are not aware of their infection accounts for 54-70% of the new infections.
- Nationally and in Wisconsin, approximately 35-40% of individuals infected with HIV do not get diagnosed until they are within 1 year of an AIDS diagnosis (i.e. "late testers"). These individuals may have been living with HIV for 8-10 years prior to diagnosis. Late diagnosis often occurs despite frequent visits to medical settings.
- Historically, HTV infection has had a disproportionately high impact on minority populations in Wisconsin. Racial/ethnic minorities comprise 12% of the Wisconsin population, but 55% of all HTV cases reported in 2008. The reported HTV infection rate in 2008 was eleven-fold greater for African Americans and five-fold greater for Hispanics compared to the rate for whites.

## Early testing and treatment are critical to breaking the chain of HIV transmission

- Individuals that are infected with HIV, but unaware of it, unknowingly transmit the virus to others.
- Research indicates that people who are aware of their infection, take steps to prevent transmission to others.
- Treatment early in the course of the disease improves quality of life and extends life for those
  infected. Treatment is also believed to reduce infectiousness and thereby decrease likelihood of
  further transmission.
- HIV screening is cost effective even if the prevalence of infection is as low as 0.01% (1:1000)
- Universal screening of all blood donors in the U.S. has essentially eliminated transfusion-related HIV transmission
- Perinatal transmission has been reduced significantly due to the routine screening of pregnant women.

#### Numerous barriers to HIV testing have been identified

- One of the barriers cited by CDC and the Institute of Medicine is the requirement for explicit written consent for HIV testing, which requires an investment of additional time in a busy health care environment.
- Patients are more likely to be tested if their physician strongly recommends it, however, many
  physicians do not do so because discussing sexual and drug risk behaviors is uncomfortable and pretest counseling takes significant time.
- Public opinion polls have shown that the majority (65%) of persons believe that "HIV testing should be treated just like routine screening for other diseases and should be included as part of regular check-ups and exams."

#### In 2006, CDC released new guidelines to increase HIV testing in the United States

- Health care providers should routinely test patients, ages 13-64 years by notifying them that testing will be performed unless the patient declines (opt-out consent).
- Separate written informed consent should not be required; general informed consent for medical care should be considered sufficient to encompass consent for HIV testing. 42 states are in compliance with this recommendation. Only 8 states still require written informed consent.
- Prevention counseling should not be required with diagnostic testing or as part of HIV screening programs in health-care settings.
- A review of 74 health professional organizations found the majority support the new CDC recommendations. Organizations fully endorsing the recommendations include the American Medical Association, the American Academy of Pediatrics, the American College of Physicians, American Academy of HIV Medicine and the Association of State and Territorial Health Officials (ASTHO)

- Rates of HIV screening are consistently higher in settings that use opt-out consent
  - o The New York City Health and Hospital Corporation serving 1.3 million New Yorkers found the number of persons tested increased 57% and the number of new HIV diagnoses doubled.
  - o A report from the San Francisco Department of Public Health showed a marked increase in HIV testing and a 50% increase in positives identified after adopting opt-out testing.

### Current Wisconsin law requires written informed consent

- Wisconsin law [s. 252.15(2) (b)] requires that prior to administering an HIV test, the health care provider must first obtain written informed consent from the test subject.
- The consent must be given on a designated form for HIV testing, which must be signed and contain all of the following:
  - o The name and signature of the test subject who is giving consent
  - o The date consent is provided
  - O A list of persons to whom and the circumstances under which statutes specify that test results may be disclosed without consent or a notice that such a list is available
- The same statute also indicates that the test subject may identify on the same form to whom the result may be disclosed. However, due to recent HIPAA requirements, the Department of Health Services has encouraged the use of two separate forms for consent and for disclosure.

#### 2009 Assembly Bill 659 modernizes Wisconsin HIV testing and consent laws

- AB 659 eliminates the requirement for written informed consent and instead requires patient notification for opt-out testing with the option to decline
- Opt-out consent is defined by the following process:
  - 1. The health care provider notifies the patient that an HIV test will be done, unless the patient declines.
  - 2. The health care providers offers a brief oral or written explanation of HIV testing, including a brief explanation of HIV infection; meaning of test results; reporting requirements; and treatment options and HIV-related services available for those who test positive.
  - 3. The patient must be notified that they may decline testing, and that this refusal may not be used as a reason to deny treatment or services.
  - 4. The subject must be given the opportunity to ask questions and decline testing.
  - 5. The provider must verify that the patient understands that testing will occur and that the decision by the patient is not coerced or involuntary.
  - 6. The consent or declination of consent must be recorded in the subject's medical record.
- AB 659 maintains patient rights by requiring that the health care provider verify that the patient understands that the test will be done and has given the patient an opportunity to decline the test.
- The patient must still provide written informed consent to disclose test results
- Penalties for illegal disclosure of test results and HIV-related discrimination have been doubled from current statutory limits.

#### In conclusion

- AB 659 will increase HIV testing in Wisconsin while maintaining patient rights.
- Through opt-out testing, more people will be diagnosed earlier and have access to life-saving
  medications, leading to an increase in quality of life for those who are infected and a gain in life
  expectancy.
- Routine HIV testing is cost-effective and cost-comparable to screenings for other diseases similar to the cost-effectiveness of colonoscopies and Pap tests.
- A recent study estimated that a national policy of routine, opt-out HIV testing would extend the lives of thousands of people, saving 610,000 life years.
- Testing is also a critical prevention strategy that decreases HIV transmission through patient behavior change after diagnosis and reducing infectiousness through treatment interventions.
- By modernizing Wisconsin's HIV statutes, HIV prevention and treatment in our state can respond to meet the challenges of a disease that still stubbornly persists in our communities.

#### LEADING WISCONSIN'S RESPONSE TO AIDS

Chairman Richards and Members of the Committee,

My name is Bill Keeton and I am the Director of Government Relations for the AIDS Resource Center of Wisconsin. I am here today on behalf of ARCW to testify in support of Assembly Bill 659 and to thank Representative Shilling and the Department of Health Services for inviting ARCW to offer feedback and insight into the drafting of a bill that will help expand HIV testing while protecting patient rights.

ARCW is Wisconsin's largest provider of HIV medical, dental and mental health care. We have offices in nine cities across Wisconsin and we also provide a vast array of both social services to help make sure people living with HIV have the greatest chance for living a long and healthy life.

Today, HIV patients have the opportunity to live a long and healthy life provided they have access to appropriate medications and medical providers. However, significant barriers to successful HIV continue to treatment exist, including two addressed by this bill:

- 1.) Late diagnosis: Many patients are not diagnosed until they have been living with HIV for a long time and they are either at or close to an AIDS diagnosis. As with many other diseases, early detection and treatment substantially increase the chances for successful treatment.
- 2.) Access to care: After being diagnosed, many patients are unsure of where to go to receive health care and support. Making sure anyone who tests positive for HIV is immediately linked into health care increases the likelihood for successful treatment.

The changes included in AB 659 will help reduce these barriers by streamlining the HIV testing process in Wisconsin while ensuring that the ability consent for testing remains with the patient. Given the stigma that is still experienced by many HIV patients, it is important that testing remains voluntary and that the law regarding consent is clear.

Additionally, AB 659 clarifies post-test counseling to ensure when someone tests positive that they are immediately given information as to where they can go to receive the health care, social services and the support they need to cope with what is a life-changing diagnosis. Wisconsin has invested in the creation and maintenance of a strong network of AIDS Service Organizations that make sure no matter where someone in Wisconsin lives, they have access to medical care, medications and the social services they need to be successful in their treatment regimens.

ARCW encourages the passage of AB 659 and applauds Representative Shilling for her hard work in building consensus on this important issue.

January 27, 2010

AB-659

HIV testing and consent revisions

Testimony of Craig Roberts, PA-C

Chairman Richards, and members of the committee, I want to thank you for this opportunity to address Assembly Bill 659. It is a pleasure to come before you again and speak about these important topics.

My name is Craig Roberts and I am a physician assistant and epidemiologist with University Health Services at the University of Wisconsin-Madison. In my role there, I am the manager of the sexually transmitted disease clinic that serves both UW-Madison students and Dane County residents, known as the Blue Bus Clinic. I am also a clinical assistant professor in the Department of Population Health Sciences in the School of Medicine and Public Health at UW-Madison. I have 30 years of experience in the diagnosis, management and treatment of sexually transmitted diseases and see patients for STD and HIV testing on a daily basis.

I am here today to speak in favor of AB 659, regarding the revision of statutes relating to HIV testing and consent. When the HIV antibody test first became available 25 years ago, there were justified concerns that people could be tested against their will, and that patients would be discriminated against just because they were tested. The Wisconsin Legislature wisely created appropriate legal protections to keep this from happening. Since that time however, HIV testing has become common, mainstream and is widely accepted. An HIV test is frequently requested by patients, and in my clinic we perform approximately 2200 HIV tests per year. Every one of those requires us to go through the process of collecting a signed consent on a paper form, then processing that form. Patients frequently ask why this is being done, since they are not required to provide written consent for any other laboratory test. It is time consuming and unnecessary since the patient has already agreed, and often requested, that an HIV test be done.

The time has come to drop the written consent requirement. It is a relic of the 1980's, an era when our understanding and approach to HIV infection was very different than today. I'm certain that the hassle of obtaining written consent has caused many clinicians to avoid even offering HIV testing to their patients, and that is unfortunate. We should be using opt-out testing or verbal consent instead. The proposed revisions to current statutes will continue to provide strong protection for disclosure of results and for patient information about testing. This bill will substantially increase the penalties for discrimination or inappropriate disclosures. It modernizes our approach to HIV testing, education and reporting and brings us into compliance with CDC recommendations and the testing practices adopted by nearly every other state.

I encourage you to support this important legislation and revise current statutes relating to HIV testing.

Thank you for the opportunity to speak before you today. I would welcome any questions you may have.



January 27, 2010

The Honorable Jennifer Shilling Wisconsin State Capitol Room 320 East, PO Box 8953 Madison, WI 53708

Re: Human Immunodeficiency Virus (HIV) Testing Modernization Bill

Dear Representative Shilling:

I am writing on behalf of Gundersen Lutheran Health System to encourage you to support the proposed HIV Testing Modernization legislation which would move the state's health care system towards more routine testing for this virus, while maintaining an appropriate level of confidentiality and respect for patient privacy.

As you know, HIV is a very serious, life-threatening infection that over 5,900 Wisconsin residents are currently facing. Unfortunately, 25% of this population is unaware of their infection, which plays a significant role in HIV transmissions. Recently, there has been an increase in the percentage of HIV infected women of childbearing age, placing the unborn at great risk. The Centers for Disease Control (CDC) now recommends all adults and teenagers be tested for HIV, especially all pregnant women as early as possible during pregnancy.

Gundersen Lutheran believes the HIV Testing Modernization Bill addresses the shortcomings of current testing practices which were written at a time when there were limited options for treatment and effective disease management. Current health code places barriers to timely testing of patients, many of whom may have inadvertently exposed health care workers. Health care workers significantly exposed to the blood from critically ill patients often need to wait until a consent form is signed before testing is done. In the meantime, antiviral prophylaxis drugs must be administered and workers face a great deal of uncertainty until the HIV status of the patient is known. This places unnecessary stress and hardship on the health care provider and their intimate contacts, not to mention the possibility of serious drug reactions.

The proposed legislation appropriately revises Wisconsin Health Code 252, consistent to current trends in disease development and recommendations by the Centers for Disease Control. At the heart of the debate is the rights and privacy of the individuals who are subjected to testing for HIV infection. They often suffer through fear, isolation, and, in some instances, discrimination. Taking into consideration the importance of patient confidentiality, sensitivity and desires, this legislation allows for patients to opt-out of testing, undertaken with the patient's knowledge and consent to general medical care. By changing the consent process, this legislation allows providers to request testing and, if patients do not disapprove, carry the testing out in a timelier fashion.

Gundersen Lutheran encourages you to support HIV Testing Modernization Legislation because it expedites the testing process and will facilitate expanded testing and disease intervention while protecting patient privacy and choice.

Sincerely,

Jeff Thompson, MD

Jeff Thopan MD

Chief Executive Officer